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JOSEPHINE AKINGBULU:

OK, everyone. Hello, my name is Josephine Akingbulu, and I would like to welcome you to the Autism Intervention Research Network on Physical Health the AIR-P August 2022 webinar. Thank you for joining us today! Because of the number of participants, your audio will be muted throughout the call, however, you can submit questions at any point during the presentation via the Q&A feature on the chat box on your webinar console. Just a funny reminder to please be respectful when communicating in the chat and asking questions, and note that the questions or comments pertaining to the presentation will be addressed.

This entire webinar is being recorded and will be available on the ARP website which I will put into the chat -- AIR-P and you can view the slides to follow the presentation on our Google Drive archive. Make sure to put both links in the chat for your perusal, and there will be a short evaluation survey at the close of the webinar. We invite you to provide feedback on this webinar and also to provide suggestions for future webinars.

In the interest of time, let's get started. We first want to acknowledge the Health Resources and Services Administration as the funding source of the AIR-P. At this time it is my honor to introduce our presenter for today, Doctor Lisa Croen, PhD, Gender, Sexuality, and Reproductive Health Node Co-leader. Doctor Croen has been a research scientist at the division of research at Kaiser Permanente Northern California since 2000, and is a director of the KPNC autism research program. I would like to also introduce Doctor Maria Massolo, PhD, Gender, Sexuality, and Reproductive Health Node Co-leader.

Doctor Marcello is a cultural anthropologist who has collaborated with Doctor Croen at the autism research program for 15 years. So, at this time, please join me in welcoming Doctor Lisa Croen and Doctor Maria Massolo.

DR LISA CROEN:

Thank you very much, Josephine. Are you going to show the slides? OK.

While she is bringing that up, I wanted to acknowledge again our funders. If you can go to the next slide.

We are able to do this work with the generous support from HRSA, and we are very excited to be part of this project.

You already -- I have already been introduced. Maria as well. If you go to the next slide, good afternoon. Our plan today is to give you a brief orientation to community-based participatory research,

otherwise known as CBPR. I will begin by providing a brief introduction to CBPR, explaining what it is, how it is done, how it differs from traditional research approaches and the benefits of taking this approach.

Then I will turn over to Maria will provide a brief history of CBPR and health research, including the establishment of the patient centered outcomes research Institute, or PCORI. Maria will then go into more depth discussing the application of CBPR in autism research, providing an overview of the groundbreaking work done by AASPIRE and finally she will focus in on the work that we're doing at AP Park -- AIR-P, Gender, Sexuality, and Reproductive Health Node Co-leader. So, to start, what is CBPR? Here's a definition that was written in 2004 which stated that community-based participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issues being studied and represented as an organization, researchers in all aspects of the research process.

The goal isn't to improve -- the goal is to improve health and well-being and taking action including social change.

There's a nice description of CBPR on the AASPIRE website that states that CBPR's approach to scientific inquiry in which scientific professionals and members of a specific community work together as equal partners to develop, implement, disseminate their research. As a form of action research, CBPR projects aim to make changes in the world that are desired by the community.

In the CBPR project, the lived experience of community members and the academic learning of scientific professionals are valued as equally powerful sources of knowledge. You will keep hearing us repeat this notion of equality, equal partnership. That is really the foundation of CBPR.

Community academic partners are expected to learn from each other and respect each other's expertise. That, again, I put that nice definition from the AASPIRE website, and Maria will tell you a little bit more about that. I want to emphasize that CBPR is just one kind of puts up a Tory research. -- Participatory.

The key elements of CBPR involve equitably involving all partners in the research process. All partners researchers and community members are informed, included and involved in all aspects of the research process. From the design to the implementation, to the dissemination of the research results.

Researchers and community members learn from each other throughout the research process, as I already said. CBPR begins with the research topic of importance to the community. This is very different from the traditional approach to research, where research ideas start with the researchers.

CBPR combines knowledge and action for social change to improve community health and eliminate health disparities. Here, I want to point out that the emphasis here is on improving community health rather than the health of an individual in the community. Also, with this goal of eliminating health disparities.

Finally, which I've mentioned already, CBPR disseminates results to all partners and involves all partners in the denominator in wider dissemination of the results. As in traditional research approaches, findings are usually published in academic journals, and that is where it may end. CBPR, the goal is to not only publish your findings, scholarly journals, but also to release findings to the press and to use these findings to influence policy, which can be done by the community advocates themselves.

So, to show this side-by-side, the traditional research approach as I've mentioned. The researcher determines the questions to be asked, the tools to be used to collect data, the mode of data collection and what interventions might be introduced to overcome the limitations and to improve health. Whereas, in CBPR, the research begins with the research topic of importance to the community.

In traditional research approach, the research team does all of the implementing, analyzing, publishing the data. In CBPR, it equitably involves all partners in the research process and in traditional research approach, data is transferred from the participant to the researcher, or extracted from the participant and used by the researcher, whereas in the CBPR approach, there is really a commitment to change this power relationship between the researcher, and the research to make them more equitable partners in the research endeavor.

So, the benefits of CBPR – I hope you have gathered from what I said, it really benefits all partners. The community participants, the healthcare practitioners and the researchers, by creating bridges between scientists and communities with the scientists study. It facilitates the development of culturally appropriate instruments. Instruments that are designed, data collection instruments, or other modes of research methods that are really appropriate for the particular community and it will work with providing valid data, information for the community being studied.

A mutual trust is established when researchers and community partners work together, which enhances the quality of the data collected and the overall quality of the research.

It affords the opportunity for researchers to gain a better understanding of the community's unique circumstances, by working together. Overall, this approach improves the quality of the research, enhances the capacity of the communities involved in participating in research, voicing their opinions and bringing their issues and their priorities to the forefront and having something acted upon, research done to overcome some barriers that they may be experiencing or knowledge gaps that they want to fill.

Ultimately, it improves health outcomes for individuals, but especially for communities.

Now, I'm going to turn it over to Maria to tell us about the history of CBPR and what we are doing specifically in our AIR-P gender sexuality and health note.

DR MARIA MASSLO:

Thank you Lisa. Regarding the history of CBPR in healthcare research, in 2000 – the origins go back

to 2001 when the agency for healthcare research and quality, a AHRQ, several federal agencies and the Kellogg Foundation, convened a two-day conference to note the use of CBPR in research -- promote, and develop strategies to promote it and to explore its use and policymaking.

The hope that this approach would improve studies for both researchers and the communities studied, and help address problems of healthcare disparities.

I want to make sure that throughout the rest of this presentation, while we are focusing on CBPR, CBPR is just one approach to inclusive research. We are going to briefly look at another one.

As Lisa mentioned, another inclusive approach is taken by the patient centered outcomes research Institute, or PCORI. You may all know that PCORI was established in 2010 by Congress as an independent nonprofit institute to do patient centered research. PCORI has since, been to -- 2010 has been a leader in driving US clinical research to become more patient centered. In their own words, they focus on outcomes that matter in -- to patients. PCORI is one of the leading institutes to find this kind of patient centered research.

To give you an idea, since 2010, they have spent about \$3 billion to fund over 2000 research and other related projects. In 2019, PCORI was reauthorized by Congress and at that point, they added additional research priorities.

PCORI funds primarily clinical effectiveness research, CER projects.

We also found the -- also fund awards to promote engagement in research, dissemination and implementation projects, methodology research and the development of research infrastructure, including PCORnet, the national patient centered clinical research network.

I think it calls for inclusive research continue in the field of autism. You have an example on the slide from Elizabeth Pellicano, who in 2020, who is asking... I'm going to read it because I think it is a valuable call to inclusive research and to respond to the needs and priorities of the community. She says, "the vast preponderance of autism research worldwide still focuses on the underlying genetic causes and biology of autism..." (Reads) This is from an earlier writing by Pellicano.

(Reads)

Even more recently, there was a call by Geraldine Dawson and other prominent researchers asking for the inclusion and voices about autism research, policy and clinical practice.

Researchers continue asking some researchers for inclusion in establishing researchers priorities that make sense of the community and yet by large, research studies are not focusing on that. And they are not inclusive.

CBPR in autism research is not new, as we are going to see. Its adoption has been relatively slow.

One exception to this, as Lisa mentioned, is AASPIRE. The academic, artistic inspection partnership in research and education.

As early as 2006, Christina Nicolaidis and Dora Raymaker, a Portland State University, establish this collaborative that continues to do research and now has expanded to members from the US, UK, Australia.

This is, again, a collaborative in which an academic community and the artistic community work together to contact research projects relevant to the needs of artistic adults -- autistic, and Christina Nicolaidis points out, another researcher, shows that while autism is a lifelong condition or disability in many cases, the research focuses continues to focus primarily on children.

AASPIRE is focusing on the lives of autistic adults. The mission, as they stated is to encourage the inclusion of autistic people in matters that directly affect them. To include autistic people as equal partners in research about autism. To answer research question, relevant to the autistic community and to use research funding to affect positive change for autistic people.

Change and affecting change is something that AASPIRE highlights and emphasizes in their work. Let's do research that is relevant and will bring up change and improvement in the lives of autistic adults.

AASPIRE has a highly recommended website with tools, resources, guidance about participatory research, accessibility and also with discussions about neuro- diversity, healthcare, employment, reproductive health, mental health and much more. It is very simple, AASPIRE.org, easy to remember. In that website, there is a great video in which Christina Nicolaidis discusses participatory research step-by-step and what to do, and what not to do. What to call participatory based research, and what kind of research should not be called participatory community-based research.

Now I want to switch it to our own work implementing CBPR at the gender sexuality and reproductive health node of the AIR-P. One of the first priorities that Lisa and I had for our node was to create a team of researchers and artistic -- autistic individuals to guide our work in this rather new area of research.

We embarked in the creation of the stakeholder advisory group in the fall of 2020. As soon the grant was confirmed.

We started searching for candidates at that point. By early 2021, we had confirmed 6 members with whom we worked for the first 2 years.

Recently, at the recommendation of the existing advisors, we added 3 new members. Our advisor group now consists of 9 members. The group is very diverse, in terms of gender identity, sexual orientation, age, ethnicity and experience. Just to give you a sense, six individuals have postgraduate degrees, to our pursuing doctorates, and all others are experienced in advocacy and community work.

In sum, members bring lived experience and expertise of both academic and advocacy expertise.

One of our members at some point suggested in the first year of working together, that is all great to have very accomplished individuals participating as researchers in our teams, but often, people in the community are not prepared to participate in research.

They are never invited to participate in research, in any capacity.

So, it would be good to build capacity, to bring capacity to the community, to bring skills and to work on skills that would be good if they were to be invited to be part of the research team.

So, in order to build capacity in the community, we coproduced with the research team and advisory board, working together to coproduce a three unit course that we piloted in the community in February 2022. February of this year.

I will tell you a little bit about the course. The course is quite simple, consists of three units, as you can see the first unit is -- goes over research, and basically we established five basic steps of research from developing the idea to the type of data that we need to answer the research question, to creating the methods, to implement the research project, to collecting data and analyzing, disseminating.

The second unit covers ethics in research. Anything that is required by a (unknown term). We spent a lot of time talking about consent and the limits and the risks of participating in research. We went a little bit over the ethics of doing research, really protecting human subjects.

Finally, unit 3 -- it focuses a bit more on CBPR and on the skills needed to be a research partner from the community in a research study that is effective communication. We spent quite a bit of communication -- time on communication, sharing ideas, working, teambuilding, and sharing those ideas, modifying those ideas.

Each one of the units were delivered virtually. Classes were two hours long and included breakout rooms, in which people did the discussion, and participants discuss the topics and came up with answers.

They were offered the units in 3 consecutive weeks. We had two goals in creating the training. One of them as I said, was to train artistic members in the community to acquire skills needed to work, research team. We also had a secondary goal which was to collect the trainees priorities about issues related to our node, gender, sexuality, health and to share them with an international panel of experts that are drafting recommendations for policy on these topics.

A little bit about the creation of the training. This wasn't iterative process, from a very rough draft and basic ideas, we went back and forth with the team, advisors about 6 times until we decided "OK, we are ready to give it a try in the community and to pilot it into the community."

One of Ed -- our advisor said, "who's going to teach the course?" And we said, "good question." We

have been thinking that the social worker could teach, but we were not clear, and we are exploring the possibilities. Until we came up with who we invited, that we have been working with, who is now part of the advisory board and who is experienced in teaching workshops in the community. They did an extraordinary job teaching this course.

We partnered with a community, organization that provides services to adults with developmental disabilities here in the San Francisco Bay area, and they focus on 3 main areas for their services. One of them is independent living skills, job training and job placement, and community engagement.

We worked very closely with one of the managers in the community to create all of the logistics which were quite complex. Also, to go over the training many times, we trained their support staff and they did the recruitment of participants.

They recruited 13 adults, autistic adults who showed an interest in the course. I am proud to say that 12 of the 13 completed all of the activities. Unfortunately, one person had encountered personal issues and had to drop out.

Like everything else, working with the community and including members in our teams, we accommodate. We provided accommodations to give an example, after the first class, one of the members wrote to us and said, "well, this is so great and I love the topic but the group class does not work for me." So, we contacted them and we offered an individual class.

A couple of other members, due to conflicts with work and other activities, they had to miss a class, they were provided individual makeup classes.

Everyone completed the full course.

As I said, supporters from the community organization, they were there to support their participants and they were known to the participants. So, to make them feel at ease. The two members in addition to myself, I was there to support the instructor, in case there were any specific questions about a research team. Two other members of the research side of the team, Lisa and another one of our colleagues, Jen, where there as observers, but also to provide support during breakout groups and discussions. And to make sure that people were feeling comfortable with the discussion.

That worked out really well. The course includes an instructor manual and currently, we are working with a fantastic team of artists, graphic designers that work as a collective at Spectrum Fusion out of Texas. There all autistic individuals and they are illustrating our slides, creating a manual for participants. In the future, we hope that when the course is offered, participants will also have a manual either to review in advance or after each unit is presented.

By the way, before each class, the slides for the class were given to participants in advance.

I also must say, as another accommodation, before the class I personally texted every one of the participants to remind them that the class was starting, 15 minutes before the class.

Finally, everyone, instructors, supporters, participants, were compensated for participating in the training.

As I said before, we have a second goal for the training. That was to obtain priorities from the communities and ideas, questions from the community to share with the team working on the INSAR policy recommendations. At the start of unit 3, being a community research partner, the instructor announced to the participants that they were going to be invited to share their ideas about what was important to them in terms of gender, sexuality and health. But, also, questions about what they might want to know about this topic.

Given the sensitivity of the topics, and the possibility that some of the participants in the training may have never talked about this issue with anyone. We also offered a 45 minute "bridge session" before the start of the focus group. In the "bridge session", we watched short films and answered questions. By the way, I should say that the short films were created by the National Council for Independent living, and they were 1-3 minutes long, and we were all presented by disabled individuals; and they are extraordinary. They are amazing tools for sexuality and gender education. I invite you all to check them out. They are available on YouTube.

I also want to share with you that the invite to the focus groups was written in part by the instructor, facilitator who was also, is also one of our advisors and an individual with -- autistic individual who is also a non-binary individual who said "sometimes, people with disabilities get left out of conversations about gender and sexuality..." (Reads)

That was what they expressed in the invitation. Again, all of the participants from the training were happy and eager to register for the focus groups.

In terms of implementation, both the focus groups and for the training, we used Jamboard. I would say that Jamboard was used more during the focus groups because that was where we were capturing the ideas, questions that participants brought up.

We also used the chat function. Finally, both as I said before, focus groups and the training included supporters.

From Jamboard, what was really wonderful was that once the ideas were all in front of us, our facilitator has an amazing ability to understand the ideas, and we were grouping them to come up with themes.

Here is a taste of what came up and what we themed sex education and consent. I will review the questions that people came up with, to give you a sense of what, again, individuals who have never been invited, never gone to a research project, or have never asked to share their ideas. This is what they came up with.

"How do autistic people learn about sexuality? From whom? Friends, school, doctor, parents?"



(Reads)

Again, this is just a taste of what ideas, questions that came up. More importantly, it were voices from the community that are helping to shape, formulate the research questions and priorities that an international group of experts are putting into policy recommendations for the international Society for autism research.

Finally, to conclude this part of the presentation, we hope that you will have some questions for us. I want to share a comment from the instructor of the research basics training, that eloquently sums up the interest of community members and being involved in research and the value of a training like the one that we created.

They said, "it is really rewarding to do this kind of work because it was clear how much the participants want to be involved with the research..." (Reads)

The instructor, Morrigan Hunter, was the one who wrote those words. Finally, a reminder, to come for all of us, is the call from the Disability Rights Advocates, and it is a powerful reminder that research leads to better outcomes when it is participatory and inclusive. To summarize beautifully saying, "nothing about us, without us."

We hope that this has inspired some of you to work on participatory research, and will be happy to answer any questions that you may have on how we did it. I want to make clear that what was CBPR for us is the work that we did, and what we continue to do with our advisory board in the creation of the training.

The focus groups had graduates from the training who were invited as research participants, but research participants want to believe that they were educated and what it means to be part of a research group. Thank you.

DR LISA CROEN:

Thank you Maria, we are happy to answer questions, speak with people if you have any questions or comments. We would love to engage with you.

Here is one, I will read out loud. "We able to engage..." –

DR MARIA MASSLO:

Everyone who was -- we asked to recruit individuals with minimally verbal, but we didn't get any takers. With people with individual disability, -- intellectual disability, we did the same thing that we did with everyone. We don't make any assumptions when we do accommodations. Let me give an example of accommodations.

Our communication with the team and with the participants, always follows a very, carefully crafted template for email. It has information about the email is about, brief description of action items, a short-

term deadline and if necessary, or if possible, a longer term deadline.

That is how communication goes out. For people with intellectual disability during the training, their supporters, personal supporters were there but they mostly dealt with issues of how to mute, unmute, and after the first meeting, they knew what to do.

We really did not have to do a lot. We may repeat questions, rephrase questions, but the instructor was fantastic at doing that.

The other thing that the instructor had no problem doing, and that Lisa and I are learning to do, is to provide people time. You ask a question, and new weights for longer than we think, sometimes when we wait. Wonderful things come out. As I mentioned before, reminders before the training worked, and even with one of our advisors, I normally send a text to point out that there is an email that should be read.

Other than that, communications with one of our... With many of our advisors, for instance, to give feedback on the training, that we did on zoom or teams, I then organize the transcripts and got the information that way.

That is all that I can think of. Lisa, can you think of anything else?

DR LISA CROEN:

I think we invited everyone to invite anyone that they wanted to support them, and the staff at the community organization who created -- included these participants, were available to guide and help assist with a few of the participants. We did end up having two groups, and they were sorted by the support needs. But, it turned out, the so-called "higher support needed group" which I unfortunately was not able to attend their sessions, Maria tells me that they were incredible, and they had so much to share. As the other so-called "lower support needed group".

DR MARIA MASSLO:

I want to clarify what Lisa just said. We did not make that distinction. The distinction, separation of the two groups had to do with when they were available for the classes and it would not interfere with their services. So, the classes were not part of the services that they normally received. We didn't want anyone to get confused about it or coerced into taking the class.

We knew that one group, a very small group that happened to be a group that needed higher support were available in the mornings, and the other groups were available in the afternoon. For the focus groups, everyone came together and the results were amazing.

DR LISA CROEN:

The thing that I really learned, and what was -- and what I was struck by, is that it is not an accommodation per se. But, having the course, focus groups taught by and led by autistic individuals

was a game changing approach. First of all, these two autistic people who are incredibly experienced leading groups, and doing this kind of activity over zoom. But, they do speak more of the same language that the participants, then I would or social worker in the community who is not autistic. Also, the group of participants, of autistic people supported each other in ways that during the sessions. They asked questions of each other, they restated what they thought they heard, they helped people articulate what they were trying to say.

In a really beautiful way.

So, it was inclusive all around with the participants, as well as the instructors, supporters, and it really flowed. As Morgan said, in the quote that Maria wrote, these individuals were so thrilled to be invited to do something like this. At the end, the third class was over, several of them said "when are we meeting next?" We said, "that is it!" And they were ready to keep going. I think it was really... They have never been invited to do something like this, and it was very valuable for them. We were really lucky with that pilot.

DR MARIA MASSLO:

One small point to add – people from East Bay innovation, support group said to us, we had wonderful focus groups with them to debrief and they said to us – first of all, we realize that we provide support to adults and we never discussed these issues with them about gender, sexuality. We don't provide support. We acquired a lot of resources now to work on this topic.

Also, their colleagues who are not involved in this pilot really wanted to extend the group to include some of their participants saying that they can also benefit from this.

And we said, "well... For now, we want to keep this just for autistic people, but in the future, there is no reason why this should not be more open to the community."

DR LISA CROEN:

To add one last thing – we had this first pilot of the research training course, and we are working on ways to manual lies, disseminate. We see this as a real benefit to researchers, communities across the country who really want to engage in participatory research. But, need to find partners. So, it is a way to invite, train up community members to be able to participate effectively as research partners. We are very excited. We don't know, quite how we are going to package it and disseminated, but that is our goal.

Here's one more question that came in. "What would you do differently to have success including minimally verbal autistics?"

DR MARIA MASSLO:

I really think that we need to be out there in the community recruiting and perhaps making it very explicit in the invites and the recruitment process, that we are looking for individuals who -- with minimally verbal, individuals to participate in these.

I think it will require the same kind of careful screening, for lack of a better term, that we did screening in terms of their needs, accommodation needs. When he interviewed each one of the advisory board members of our team, we met with them and discussed at length, what do you need to be your best? To offer, share, and to make you comfortable? How do you communicate best? Often times – in our big meetings, we have two big meetings a year, and many people are not on-screen. They don't even talk. They share their ideas via chat. So, someone is in charge of checking the chat and ensuring that their voices come through.

So, I would say that logistics are very important, preparing for accommodations, but primarily, asking people – "what do you need?"

DR LISA CROEN:

When we didn't have any minimally verbal people in our training course, but many people do choose to communicate by typing. Our meetings have been virtual, that is the benefit of this pandemic, forcing us all to be virtual, but it has allowed different modes of communication for people. Often, we are going in between the chat and the verbal, and some people do both. As Maria said, some people are on or off camera. It really works out. It allows people to communicate and participate in what works best for them.

I think we are out of time?

JOSEPHINE AKINGBULU:

We are out of time, thank you so much to our presenters for your work in this area and we appreciate all of the great questions. We encourage everyone to attend our next webinar with Doctor Denise Nunez in September. I've included a few links into the chat if you would like to learn more access some of the videos. It will be archived on our YouTube channel. Once again, thank you for your time, and we ask you to take the survey in the chat and we will see you next time! Thank you so much!

DR LISA CROEN:

Thank you very much.

DR MARIA MASSLO:

Thank you.

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